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ABSTRACT

A study was conducted with a sample of 80 black mothers of mildly to profoundly mentally retarded children in the Pretoria, South Africa, townships of Atteridgeville and Mamelodi. The study sought to identify support systems utilized by the mothers, identify latent systems that could be supportive to the mothers, ascertain the extent to which existing systems are utilized, and identify systems having negative effects on the families. Interviews with the mothers resulted in the following findings, among others: (1) tasks with which most mothers/caregivers required aid were bathing and dressing the child and doing the laundry; (2) more than half of the mothers needed financial assistance because of expenses related to their child's condition; (3) informal support systems consisted of the child's father, the mother's siblings, relatives, friends, neighbors, and the siblings of the child's father; (4) formal support systems consisted of a social worker, a doctor, and a priest; (5) more regular contact existed with the informal support system than with the formal system; (6) generally, respondents were not aware of existing services in their communities, with the most well-known services being general child welfare services and services for disabled children. (Author/JDD)

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Support systems of mothers of mentally retarted children

E.N. Chinkanda

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Support systems of mothers of mentally retarded children

E.N. Chinkanda

Pretoria
Human Sciences Research Council
1987

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ABSTRACT

From the end of 1985 to the beginning of 1986 the Social Work Division of the Institute for Sociological and Demographic Research conducted an exploratory study among a sample of 80 black mothers of mentally retarded children in the Pretoria townships of Atteridgeville and Mamelodi.

The study tried to ascertain who the people were that assisted the mothers of the mentally retarded children in caring for their children at home, whether the mothers did in fact require assistance and the areas in which help was needed.

The conclusions drawn from the study were that the mothers did require emotional and instrumental support and that the tasks for which most help was needed were bathing and dressing the children, and doing the laundry. The major sources of support were the fathers of the children, the mothers' own siblings and grown-up children.

SAMEVATTING

Aan die einde van 1985 en die begin van 1986 het die Maatskaplikewerk afdeling van die Instituut vir Sosiologiese en Demografiese Navorsing 'n verkennende studie onderneem met 'n steekproef van 80 swart moeders van verstandelik gestremde kinders in die swart woonbuurtes Atteridgeville en Mamelodi.

Met die studie is gepoog om vas te stel wie die mense is wat die moeders van verstandelik gestremde kinders help met die versorging van hulle kinders tuis, of die moeders in werklikheid bystand nodig het en op watter gebiede die hulp nodig is.

Die gevolgtrekkings wat op grond van die studie gemaak kon word, was dat die moeders emosionele en instrumentele steun nodig het, en dat die bad en aantrek van die kinders, asook die behartiging van die wasgoed die take is wat die meeste hulp vereis. Die hoofbronne van steun was die vaders van die kinders, die moeder se broers en susters en volwasse kinders.

SUPPORT SYSTEMS OF MOTHERS OF MENTALLY RETARDED CHILDREN

1. STATEMENT OF THE PROBLEM AND METHOD OF INVESTIGATION

Statement of the problem

For centuries the history of the care of the mentally retarded was typified by institutionalization. Recently, however, there has been a shift from institutional care to community care for two important reasons (Payne, Mercer 1975). As knowledge about mental retardation increases, it appears that society is becoming more understanding and tolerant of those suffering from such a handicap, which makes their care within the community a possibility. On the other hand, the number of mentally retarded people has increased proportionately with the increase in the world population, and their lifespan has also increased. This has made institutional care an expensive undertaking, both in terms of quality and quantity for any government.

The care of the mentally retarded in the community appears in most cases to be undertaken by the family. Community care as perceived by Wilkin (1979) refers to the care of the handicapped person within his family with minimum support from the state. Whereas the mildly and moderately retarded will benefit in most cases from community care, it appears desirable to care for the profoundly and severely retarded in institutions.

The actual care of a retarded individual in the family is normally undertaken by the mother or another adult female who has been assigned the responsibility of caring for him.

Since caring for a mentally retarded child can be a very demanding undertaking for any one person, the mother or caregiver, needs to have adequate internal coping resources, but normally also requires external support from her social network in order to cope with such a child.

The Social Work Division of the Human Sciences Research Council (HSRC) is currently undertaking research on the main theme of "Intervention to enhance family life", which has been identified as a research priority (Snyman 1984). The present study has been conducted in response to

an identified need for studies of community support networks within the context of the above theme.*

Concepts in the study

For the purpose of this study the terms mentally retarded, handicapped/disabled (child/person) and retarded (child/person) have been used interchangeably to refer to a person whose mental development is deficient or retarded, who shows a marked lack of intelligence either temporarily or permanently and who therefore fails to adapt to his environment.

More specifically, the use of the term mental retardation adopted in this study is based on the definition of the American Association on Mental Deficiency (AAMD), namely that "Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, manifested during the developmental period" (Robinson, Robinson 1976:30).

The various classes of the mentally retarded are reflected as follows in the AAMD manual:

Terminology	IQ score**
mildly retarded	55-69
moderately retarded	40-54
severely retarded	25-39
profoundly retarded	24 and below.

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* This theme emerged during the third phase of a study involving leaders in the field of social work teaching and practice (see Snyman 1984).

** The cut-off score between the different groups differs according to whether the standard deviation of the test is 16 as in the Stanford-Binet or 15 as in the Wechsler scales and other tests.

In addition to the IQ scores the different groups can also be classified according to the behavioural characteristics that are peculiar to each group (Hallas, Fraser, MacGillivray 1978; Robinson, Robinson 1976; Benton 1964). The most common characteristic of each group appears to be intelligence deficiency.

A brief outline of the characteristics of each group follows:

(a) The mildly mentally retarded

Individuals diagnosed as mildly mentally retarded are often detected only when they are already at school, as they in most cases remain in one class for more than a year. Even when there are special education facilities at their disposal, such individuals pose a learning problem and normally progress to primary school level only. Most of them are able to lead independent lives as adults and are able to write at least a few words and also have an adequate knowledge of figures that will meet their everyday needs. However some may require assistance with their social and financial affairs. While some of these persons hold down jobs such as assisting skilled workers, cleaning, harvesting and are also able to master certain simple skills others will find sheltered workshops more appropriate. The women in this group are "... capable of adequate married life" (Robinson, Robinson 1976:363). Although they may find the skills required for marriage far more manageable than the demands of public life, they may not be able to provide an optimal environment for their children.

(b) The moderately mentally retarded

Unlike the above group, many of the moderately retarded have additional handicaps - physical, social and/or emotional that may hamper their progress towards achieving a successful adult life. Self-care is usually the focus of attention in training programmes for this group because of the difficulties they experience in caring for themselves and because of their need for supervision. They can however remain in their families, can adapt well to their neighbourhood and a few of them are able to hold down routine jobs such as lawn mowing, laundry and simple assembly.

Their speech is simple and concrete but usually understandable. The majority of this group however never marry and very few bear children.

(c) The severely mentally retarded

This group functions intellectually below the level of children half their age. They respond to teaching in an environment similar to that of a nursery school, but that has a more structured approach. They are capable of communicating orally and are also able to respond to verbal instructions. These persons are likely to have sustained neurological damage that further restricts their social behaviour. Most are mobile and are able to clothe and feed themselves and are also able to attend to or indicate their toilet needs. They can acquire self-help skills through prolonged, careful and supervised practice. Although very little independent behaviour can be observed, most are able to find their way around the neighbourhood. Their verbal skills are extremely limited and verbal communication consists of two or three word sentences. Although the majority in this group are incapable of leading full independent adult lives, they can benefit from sheltered work or from attending an adult day care centre.

(d) The profoundly mentally retarded

This group of retardates differs from the other three groups in respect of their level of awareness. They are apparently unaware of their surroundings and require various kinds of constant sensory stimulation - that is, in terms of sight, sound and touch. They may respond to such stimulation and these responses may eventually become spontaneous. This particular group requires a considerable amount of supervision, and because many of them are not mobile they require help with feeding and toileting. They are considered incapable of benefiting from any type of training. Because of the neurological damage suffered most of them remain at home and are bedridden or wheelchair bound.

For the purpose of the present study a social network comprises those individuals with whom one is in long-term interaction. Such a network can be formal as well as informal. An informal social network can be made up of immediate family members, relations, neighbours, friends,

co-workers and fellow club members, whereas a formal network comprises societal institutions such as welfare organizations, mental health clinics, educational institutions and financial houses.

If a person receives material or instrumental aid, information (about the environment/services) or feedback on behaviour from a network member, and this makes him feel loved, cared for, esteemed and valued, then this is understood to be social support. The support that a person receives may however differ in kind from one source to the other and also at various points in time.

The actual helping transactions can be classed broadly as emotional support, tangible aid and services, cognitive guidance and companionship.

Caplan (1974) perceives social support as involving the following:

(a) Significant others help the individual mobilize his psychological resources and master his emotional burdens.
(b) They share his tasks.
(c) They provide him with money, materials, tools, skills, and cognitive guidance to improve his handling of the situation.

The social support received by an individual can come from established institutions in the community or from natural or spontaneous support groups.

The terms social support systems and social support networks are used in the present study to refer to those individuals or groups who give a person emotional, personal and instrumental aid that enables him to deal more adequately with a problem situation. The support system also gives the individual opportunities for feedback about himself.

In their definition of social support Shumaker and Brownell (1984) speak of an exchange of resources. The "exchange" introduces an element of reciprocity in the support process, such reciprocity taking place within the realm of informal support systems and seldom within formal support systems. Reciprocity implies certain expectations between the

parties and this can place some constraints on the process of support, and may also generate stress, especially if one party is unable to return the kindness shown.

However, Unger and Powell (1980:571) perceive such reciprocity as being highly associated with interactional stability and effective functioning. Norms of reciprocity and equity suggest that recipients of support should repay the support received. A disadvantage here is that people will in all probability be reluctant to receive aid if reciprocity engenders feelings of superiority in the giver and inferiority in the receiver.

In this study a support system/network has been operationalized to refer to immediate family members, relations, friends, neighbours and institutions in the community that help the mothers/caregivers of the mentally retarded children. The informal support system comprises immediate family members, relations, friends, neighbours and other community members such as church groups, women's organizations and voluntary groups. The formal support systems include all the institutions (governmental or government sponsored) that render health, educational and welfare services.

For the purposes of this study the term mother is used to refer to the adult female who cares for the mentally retarded child. This includes the biological mother, the foster or adoptive mother, the older sister or grandmother and other adult female relatives or non-relatives who have been assigned the responsibility of caring for the mentally retarded child. This person will also be referred to as a caregiver throughout the study. The presence of a caregiver does not necessarily imply the absence of a mother. Rather, because in some cases mothers have to work full time, the responsibility of caring for the child is assigned to someone else.

The aims of the study

The study has the following primary aims, namely to

(a) identify and describe any support systems that are utilized by a group of black mothers/caregivers of mentally retarded children in Mamelodi and Atteridgeville;

(b) identify and describe latent systems that could be supportive to these mothers/caregivers;

(c) ascertain the extent to which existing systems are utilized;

(d) identify and describe systems having some negative effects on such families.

A secondary aim is to identify those circumstances where institutionalization of the child is the only alternative.

Method of investigation

A structured interview schedule was used to conduct interviews with 80 mothers/caregivers in Mamelodi and Atteridgeville.

The sample was drawn from caregivers of 148 mentally retarded children who made up the caseload of the social worker of the Pretoria and Northern Transvaal Mental Health Society. The universe was distributed as follows: Mamelodi - 95 and Atteridgeville - 53.

A quota sample was drawn to include mothers of different age groups (those aged 39 and below formed one group and those aged 40 and older another group). Different groupings of marital status were also taken into account. The reason for such groupings was an attempt to obtain a sample with mothers of different age groups, i.e. younger and older mothers of different marital statuses. A similar consideration was given to the children who were grouped according to sex and two major age groups, i.e. those aged 14 and older forming one group and those aged below 14 forming another group. A sampling matrix of all 148 case records was constructed based on the above considerations.

The interviews were conducted by the researcher and five social workers. None of the social workers were employed by the Pretoria and Northern Transvaal Mental Health Society at the time of the study.

2. DEMOGRAPHIC VARIABLES

Characteristics of the sample

Because use was made of two samples in the study, the demographic characteristics of the two samples will be dealt with separately. The characteristics of the mothers/caregivers are reflected in Table 1 and those of the mentally retarded children in Table 2.

Almost three-fifths of the caregivers were living in Mamelodi at the time of the study. The impression may be created that there are more mentally retarded children in this area than in Atteridgeville, but this is not necessarily the case. The sample was drawn from the social worker's files, which reflected the names of only those children who came to her attention. Furthermore, in the homes where more than one mentally retarded child was living at the time of the study, only the oldest child of such a case was considered for the study.

Nearly three quarters of the caregivers were in the 31 to 60 age group. Two-fifths of the respondents were in full time employment at the time of the study. Eighty-three comma eight per cent of the caregivers were the biological mothers of the mentally retarded children.

Table 2 creates the impression that there are no mentally retarded children below the age of four in the two areas studied. However, it is possible that

(i) parents may be reluctant to bring to the attention of a helping professional the fact that they have a mentally retarded child at that age because they may still be uncertain of the diagnosis or be reluctant to accept the diagnosis.

TABLE 1

DEMOGRAPHIC VARIABLES OF THE MOTHERS*

	%
Residential area	
Atteridgeville	41,2
Mamelodi	58,8
TOTAL	100,0
Age	
21-30	11,3
31-40	26,2
41-50	26,2
51-60	20,0
61-70	15,0
71-80	1,3
TOTAL	100,0
Marital status	
Married	53,8
Living together as husband and wife	1,3
Never married	20,0
Divorced/deserted/separated	10,0
Widow	15,0
TOTAL	100,0
Educational qualification	
None - never attended school	18,8
Std 3 or lower	16,2
Std 4 to Std 5	20,0
Std 6 to Std 8	33,8
Std 9 to Std 10	6,2
Std 10 plus 1 or 2 years further training	3,8
Std 10 plus 3 or more years further training	1,3
TOTAL	100,0
Types of employment	
Full time	40,0
Part time	3,8
Other (for e.g. own business)	10,0
Unemployed	46,2
TOTAL	100,0
Income per month	
Less than R100 (including no income)	8,8
R100-R299	28,8
R300-R499	16,2
R500-R699	6,2
R700-R899	1,3
More than R900	8,8
Don't know	30,8
TOTAL	100,0
Relationship to mentally retarded child	
Biological mother	83,8
Grandmother	10,0
Other for e.g. aunt, sister, etc.	6,3
TOTAL	100,0

*N = 80.

TABLE 2

DEMOGRAPHIC VARIABLES OF THE MENTALLY RETARDED CHILDREN*

	%
Sex	
Male	62,5
Female	37,5
TOTAL	100,0
Age	
4-6	2,5
7-10	16,2
11-15	28,8
16-18	22,5
19 and older	30,0
TOTAL	100,0
Medical diagnosis	
Mental retardation	91,2
Down's syndrome	7,5
Spina bifida	1,3
TOTAL	100,0
Level of retardation	
Mild	36,2
Moderate	23,7
Severe	17,5
Acute/Profound	5,0
Multiply handicapped	5,0
Unsure/information not available	12,5
TOTAL	100,0

* N = 80
More than three fifths of the children were males and a little more than a third were classified as mildly retarded.

(ii) parents at this stage may be hoping that their child will show improvement and therefore will postpone bringing him to the attention of the helping professions;

(iii) many parents begin looking for help when the child is at school going age and shows a lag in his development.

3. THE MENTALLY HANDICAPPED CHILD IN THE FAMILY

The presence of a handicapped child in a family is often met with different reactions by the various family members. Some families decide on institutionalization even where the child has no major physical impairments while others will refuse to institutionalize the child even though he is multiply handicapped and difficult to care for.

Research has shown that many mothers are not in favour of separating from their children, even when these children prove difficult to care for at home (Wilkin 1979; Hallas, Fraser, MacGillivray 1978). The feeling appears to be much stronger in cases where the child is mentally impaired. It is not surprising, then, that as many as 80 % of mentally retarded children remain at home in the care of their parents (Bicknell 1982:598).

Under normal circumstances, raising a child can be a fulfilling as well as a stressful experience. Raising a mentally retarded child however can - as the literature suggests - be particularly stressful because of the crises that are a typical feature in the lives of families of a mentally retarded child (Glendinning 1986; McCormack 1978). Such crises relate to the parents' reaction to the child's condition as well as to the day-to-day management of the child, especially where the problem of mental retardation is compounded by physical deformity (Robinson, Robinson 1976).

In addition to these crises the mother of the mentally retarded child in many instances has to cope with problems at two levels, i.e. those problems centred around the daily activities of caring for the child, as well as meeting the material needs involved in caring for the child at home.

While both parents of a handicapped child share the responsibility of caring for the child, the mother as the homemaker most often has to deal with the day-to-day tasks of caring for the child (in some cases on her own).

Caring for a mentally retarded child at home can result in major changes in the family finances, leisure activities and general life-style. For example the family budget may be strained by the inclusion of special food types, special equipment or clothing, a higher medical, electricity or fuel bill and the cost of special transport if the family has no transport of its own (Robinson, Robinson 1976). Depending on the extent of the child's handicap or on whether he has behavioural problems that call for constant supervision in order to prevent him from hurting himself and or others, the family may also need hired help.

In the present study the needs of the respondents in raising their handicapped children were expressed as follows: financial (46,2 %,) medication (15,0 %); special transport (15,0 %); ordinary transport (but convenient) (12,5 %) and hired help (11,2 %). In addition to the items listed in the questionnaire, some caregivers mentioned that they needed a training or handicraft centre where their children could be trained or could acquire certain skills.

The above group of respondents who required some form of help made up 73,7 % of the total sample. However there was an overlap in the needs expressed by the respondents and 33,7 % required only a single form of aid. Almost half of the respondents mentioned that they required financial assistance.

When asked what they considered to be serious problems in raising their handicapped children, the respondents provided the following information (Table 3):

TABLE 3

TYPE OF PROBLEM CONSIDERED AS SERIOUS BY MOTHERS IN RAISING THEIR HANDICAPPED CHILDREN

Problem	%
Social stigma	37,5
Adjustment/attitude of siblings	12,5
Adjustment/attitude of relatives	12,5
Adjustment/attitude of friends/neighbours	25,0
Physical demands of caring for the child	28,8
Disciplinary problems	36,3
Money problems	60,0
Lack of services	33,8
Lack of a suitable institution	38,8
Restriction of movements	37,5

As before, money was mentioned by the largest single percentage of respondents as a serious problem (60,0 %).

The daily care activities of mothers of mentally retarded children usually involve feeding, bathing, dressing, toileting and carrying the mentally retarded child from one point to another (Glendinning 1983; Wilkin 1979).

In the present study 14,0 % of the respondents indicated that they required help with only one task in the daily care of the child, 30,0 % required help with more than one task while the remaining 56,0 % did not need any help at all. The different tasks were bathing, feeding, dressing, toileting, laundry and keeping an eye on the disabled child.

Of the mothers requiring assistance with more than one task the main tasks revolved around bathing (25,0 %) and dressing the child (23,7 %),

and laundry (20,0 %). Only one respondent mentioned requiring help with all the tasks mentioned earlier.

Although all the children concerned in the study were retarded at different levels and could be considered as noted by Schilling and Schinke (1984) to have "... impairments in adaptive behavior", some of them were able to function independently. The areas in which three quarters of the children in this study could function independently involved the tasks defined by Ayer and Alaszewski (1984) as personal care tasks, i.e. bathing, dressing, feeding themselves or even walking. A little more than half of the children could also catch a bus or use the toilet on their own. Only about a third of the children were able to perform domestic chores on their own or with help.

Thirty five per cent of the children were reported to have physical disabilities and only 6,0 % were bedridden, and therefore totally dependent on the caregivers at the time of the study.

4. THE MOTHER OF THE MENTALLY RETARDED CHILD AND FORMAL AND INFORMAL SUPPORT SYSTEMS

The question may be posed as to how mothers of mentally retarded children cope in caring for their children at home, i.e. whether they receive help or not and how effective such help is. It has been noted that some mothers have what may be termed "personal coping mechanisms" that enable them to manage on their own without using external resources. Such personal coping strategies include contrasting one's situation with that of others less fortunate than oneself, praying, and seeking more information on the problem and on the available resources in the community (Schilling, Schinke 1984; Hymovich, Baker 1985).

However it is possible that mothers may find that their attempts at coping do not always yield the desired result. In such cases they will require external support to sustain them (Schilling, Schinke 1984, Ayer, Alaszewski 1984; Wilkin 1979).

Such external sources are referred to as social support systems or simply as support systems, which may be either formal or informal.

In discussing the role of social support in an individual's life, Gottlieb (1983:46) notes that "... people who are socially isolated or who have little access to social support are at a greater risk of ill-health and are likely to experience a greater number of environmental stressors than those who are socially integrated or who have access to social support".

The informal support system of the mother of a mentally retarded child is usually made up of several persons who may be categorized according to whether she has direct or indirect contact with them, their geographical distance from the mother, and whether they share a common problem with her or not (Allan 1983). The different sources of informal support include the immediate family, relatives, friends and neighbours (Wilkin 1979; Glendinning 1983; Ayer, Alaszewski 1984).

In this study the respondents identified the following persons as members of their informal system: their own siblings, the fathers of the mentally retarded children, the respondents' present husbands (who were not the fathers of the child in question), grown-up children, relatives, friends and neighbours.

The type of support received from these persons is reflected in Table 4.

From Table 4 it would appear that the support received from the informal support system differs from one source to the other and also on the basis of whether it is regular or occasional support. The type of support received by most caregivers is what may be termed instrumental and emotional. Instrumental support according to House, as cited by Thoits (1982) and Kaplan, Cassel and Gore (1977) refers to, among other things, help with family work or responsibilities and financial aid.

In as far as the tasks involving the day-to-day care of the child are concerned, respondents again differed on the tasks for which they required and received help and whether the help received was adequate or not. The responses are given in Table 5.

TABLE 4

TYPE AND SOURCE OF HELP

Source of help		N	Type of help: Emotional	Informational	Instrumental	Feedback on behaviour	Referral to a service	Total
Father of the child	Regularly	36	38,9	2,8	55,6	2,8	-	100,0
	Occasionally	38	26,3	15,8	42,1	13,2	2,6	100,0
Present husband (but not the father of the child)	Regularly	7	28,6	-	57,1	14,3	-	100,0
	Occasionally	6	50,0	16,7	16,7	16,7	-	100,0
Siblings of father of the child	Regularly	17	52,9	11,8	17,6	-	17,6	100,0
	Occasionally	22	22,7	36,4	27,3	4,5	9,1	100,0
Own siblings	Regularly	46	58,7	15,2	26,1	-	-	100,0
	Occasionally	53	26,4	17,0	47,2	5,7	3,8	100,0
Grown-up children	Regularly	44	31,8	9,1	52,3	6,8	-	100,0
	Occasionally	45	20,0	28,9	40,0	6,7	4,4	100,0
Relatives (of mother and father)	Regularly	35	42,9	14,3	40,0	2,9	-	100,0
	Occasionally	39	33,3	25,6	33,3	2,6	5,1	100,0
Friends/neighbours	Regularly	27	44,4	18,5	22,2	3,7	11,1	100,0
	Occasionally	40	30,0	25,0	22,5	2,5	20,0	100,0

TABLE 5

TASKS FOR WHICH HELP IS REQUIRED AND/OR RECEIVED

Task for which help is required	N	Does get sufficient help	Needs help but does not get it	Does get help but would like more	Does require help but for crises only		Total
					And gets it	Does not get it	
Feeding	12	66,6	16,6	8,3	8,3	-	100,0
Bathing	24	62,5	12,5	8,3	12,5	4,2	100,0
Laundry	21	61,9	19,0	9,5	4,7	4,7	100,0
Carrying	11	36,3	18,1	27,2	18,1	-	100,0
Dressing	22	68,1	13,6	4,5	9,0	4,5	100,0
Toileting	13	46,1	15,3	15,3	15,3	7,6	100,0

At the time of the study most of the mothers who needed help with the above tasks appeared to be receiving the help required. The tasks for which the largest single percentages of mothers needed help but were not receiving such help were laundry, carrying and feeding the child.

The extent to which a mother receives practical help with the day-to-day care of a mentally retarded child will depend on, among other things, the contact that she has with her informal social network (Ayer, Alaszewski 1984). Wilkin (1979) found that relatives who lived with the family of the handicapped child proffered more support than those who lived elsewhere. The mother's/caregiver's contact with the informal social support system, in the present study, is reflected in Table 6.

Some of the respondents mentioned that they had contact with their relatives only during school holidays, because they could then leave the handicapped child in the care of his school going siblings. One respondent mentioned a witchdoctor as a member of her informal support system and that she only had irregular contact with him. Others mentioned that they saw their boyfriends, church members and relatives such as nieces and nephews on a regular basis.

TABLE 6

TYPE OF CONTACT WITH RESPONDENTS' INFORMAL SUPPORT SYSTEM

Person(s)	N	Regularly: at least once a month	Irregularly: only when the need arises	Other* basis	Total
Father of the child	48	79,1	8,3	12,5	100,0
Siblings of father	27	59,2	25,9	14,8	100,0
Own siblings	61	63,9	27,8	8,1	100,0
Relatives	47	55,3	27,6	17,0	100,0
Friends	39	43,5	30,7	25,0	100,0

* This referred to periods such as school holidays or special occasions.

Formal support systems are defined by Lentjies and Jonker (1985:6) quoting the Wolfenden Report as "... governmentally mandated or sponsored professional services, whether state administered or provided through chartered intermediaries such as private non-profit organizations".

The formal support systems of mothers of mentally retarded children are usually made up of professionals from educational, welfare and health institutions within the community (Wilkin 1979; Glendinning 1983; Ayer, Alaszewski 1984). In the present study the caregivers mentioned that they had had contact with the following persons in the formal support system: the social worker (75,0 %), doctor (64,0 %), nurse (45,0 %), teacher (49,0 %), priest (35,0 %) and crèche or nursery school teacher (6,3 %). The regularity of the contact with their formal system also differs, as in (Table 7).

In comparison with the other professionals a priest in particular appeared to have more regular contact with a large number (67,8 %) of the mothers; they considered him to be supportive. The probable reason is that the respondents who are practising Christians are more likely to be in contact with their priest on a regular basis. Some priests visit members of their congregation at home, especially if such members are regular church goers.

TABLE 7

TYPE OF CONTACT WITH RESPONDENTS' FORMAL NETWORK

Professional	N	Regularly: at least once a month	Irregularly: only when the need arises	Other basis*	Total
Social worker	60	6,6	76,6	16,6	100,0
Doctor	51	35,2	58,8	5,8	100,0
Nurse	36	33,3	55,5	11,1	100,0
Teacher	39	17,9	46,1	35,8	100,0
Priest	28	67,8	21,4	10,7	100,0
Crèche or nursery school teacher	5	20,0	60,0	20,0	100,0

* "Other basis" explained by some respondents as "when there is a problem", "when the child is ill" or "when there is a parents' meeting".

Although mothers of mentally retarded children usually need to be in contact with professionals from service agencies because of the nature of their children's condition, they often do not know where to find such professionals (Gallagher, Beckman, Cross 1983). The mothers are also sometimes confused by the procedures for applying for assistance, and this may discourage them from approaching existing services for assistance (Glendinning 1983).

It was found in this study that the mothers had little knowledge of existing services and facilities in their communities. Table 8 details the situation in respect of the mothers' knowledge, utilization and experiences of certain community services at the time of the study.

The service known to most mothers and the one which at the time of the study had been utilized most, was the welfare service for mentally retarded children. The least known and least utilized service was the clinic offering genetic counselling services.

It appears that in the process of raising their disabled children, mothers establish a network from which they draw support on an occasional or regular basis, a network that they have experienced as helpful

TABLE 8

RESPONDENTS' AWARENESS OF COMMUNITY RESOURCES

Service or facility		There are no such facilities	I do not know of such facilities	I know of such facilities but have never needed them/didn't get round to using them	I know of such facilities and have tried to use them but found them unsatisfactory	I know of such facilities and have used them and found them satisfactory	Total
Welfare service	for children (child welfare)	1,3	43,8	48,8	1,3	5,0	100,0
	for mentally retarded children	-	13,8	11,3	12,5	62,5	100,0
	for crippled children	1,3	50,0	41,3	1,3	6,3	100,0
Special clinic	for cripples	12,5	76,3	6,3	1,3	3,8	100,0
	for mentally retarded children	16,3	71,3	3,8	1,3	7,5	100,0
Protective workshop		17,5	68,8	6,3	2,5	5,0	100,0
Day care centre		1,3	48,8	13,8	12,5	23,8	100,0
Clinic offering genetic counselling services		18,8	77,5	1,3	-	2,5	100,0
Training centre		20,0	43,8	12,5	5,0	18,0	100,0

and reliable and to which the mothers would readily refer others in similar circumstances.

Although, as noted earlier, a large number of respondents mentioned that they had irregular contact with professionals and a few reported satisfactory outcomes from such contact, 63,0 % of the respondents indicated that they would refer other mothers of mentally retarded children to professionals and formal institutions. Slighty more than two-fifths (43,8 %) mentioned that they would suggest to mothers in distress to turn to the fathers of their handicapped children and also to their own siblings when in need of support. The group mentioned by the least number of mothers (13,8 %) are the siblings of the fathers of the children.

Caplan (1974) has drawn attention to another type of informal support system, i.e. one made up of persons who have had similar experiences to that of the caregiver, in this case other mothers of mentally retarded children. In this study less than half of the mothers (48,8 %) said that they knew of other mothers of mentally retarded children, and almost a third (30,0 %) said that they had had some contact with them.

According to Shumaker and Brownell (1984), Unger and Powell (1980) as well as Lentjies and Jonker (1985) the extent to which a person receives support is sometimes determined by the extent to which he also proffers such support to others. In the present study, when asked aboul their reactions towards requests for assistance of various kinds a majority of the caregivers mentioned that they were not approached with requests for help. Only in cases of bereavement or during a crisis did almost three-quarters indicate that they had profferred support (comfort) to others. Table 9 details the respondents' reactions to requests for various kinds of assistance during a specified period.

TABLE 9

RESPONSES TO REQUESTS FOR VARIOUS TYPES OF ASSISTANCE SIX MONTHS PRIOR TO THE STUDY

Type of help requested	I have not been asked for help during this period	I tried to help every time	I sometimes tried to help	I did not help		I helped but did not really feel like it	Total
				because I was unable to	because I did not want to/ did not really feel like it		
Financial aid	43,8	22,5	8,8	25,0	-	-	100,0
Material things but not money (e.g. clothing, food, etc.)	41,3	35,0	15,0	8,8	-	-	100,0
To perform a task (e.g. care for a child, do laundry, cook, etc.)	53,8	26,3	7,5	11,3	-	1,3	100,0
Information (directions to a place, advise about a service, etc.)	51,3	36,3	7,5	5,0	-	-	100,0
Comfort (during bereavement or crisis)	17,5	72,5	8,8	1,3	-	-	100,0

5. INSTITUTIONALIZATION OF THE MENTALLY RETARDED CHILD

While some mentally retarded children can be cared for at home, others need to be placed in institutions under professional care. There are different reasons why parents sometimes prefer to place their children in institutional care. Both parents may be in full-time jobs or the child's condition may be severe and an institution would be the most suitable place for him (Ayer, Alaszewski 1984, Glendinning 1983).

In the present study it was found that 33,8 % of the caregivers wished to have their mentally retarded children institutionalized. Close on two-thirds (64,3 %) of the respondents whose children were severely retarded expressed a wish to have them institutionalized, as did three-quarters (75,0 %) of those having multiply handicapped children.

6. DISCUSSION

This study has been basically exploratory in nature in so far as it has aimed at identifying: support systems utilized by black mothers of mentally retarded children, latent systems that could be supportive and systems that were not supportive to the respondents. Another aim was to identify cases of mentally retarded children whose caregivers preferred to have them institutionalized.

The following emerged from the study:

- The majority of the children could dress, bathe and feed themselves and could be considered to be relatively independent.
- A negligible proportion of the children had disabilities that rendered them dependent.
- The tasks with which most mothers/caregivers required aid were bathing and dressing the child, and doing the laundry.
- More than half of the mothers needed financial assistance because of expenses related to their children's condition.

- The caregivers' informal support systems rendered mostly emotional and instrumental help.

- The persons mentioned by the majority of the respondents as their informal support system were the fathers of the children, the mothers' own siblings, relatives, friends and neighbours and the siblings of the father of the mentally retarded child.

- The majority of respondents mentioned all the above persons (where such a person existed or where they had contact with him/her) as members of their informal support system, while others mentioned only some.

- The siblings of the caregivers proffered support to the largest group of mothers. Grown-up children were mentioned by the second largest group while the fathers of the children, as well as the relatives were mentioned by the third largest group.

- In as far as the formal system was concerned a social worker and a doctor were mentioned by more than half of the respondents as sources of support, although a priest appeared to have had regular contact with a majority of the respondents who mentioned him as a source of support.

- Generally speaking there appeared to be more regular contact between respondents and their informal support system than with their formal support system.

- It would appear that on the whole the respondents were not aware of existing facilities (services) in their communities.

- Services known to a majority of respondents were general child welfare services and services for disabled children (physically and mentally).

- There appeared to be very little contact among the mothers of mentally retarded children.

- Although by and large the caregivers had little contact with professionals and community services, a large proportion indicated that they would refer another mother of a mentally retarded child to a professional.

- Respondents generally appeared to receive few requests for assistance from others.

- Those mothers who would prefer to have their mentally retarded children put in an institution constituted a minority.

7. CONCLUSION

Based on the findings of the present study it would appear that the caregivers needed assistance (support) of a material (financial), instrumental (practical help) as well as of an emotional nature in caring for their mentally retarded child at home.

Although most of the children in question appeared to be able to perform personal care tasks with little or no help at all, some caregivers still required help with day-to-day activities such as bathing and dressing their children. However most of the mothers/ caregivers did receive adequate assistance with those tasks for which they required help.

According to Ishabalala (1986) the custom in black families in South Africa is that the fathers' siblings are mostly involved in the raising of children and that the families generally have built-in supportive networks. These statements were however not supported by the findings of the present study. The support received from the family, especially from the fathers' siblings appeared to be minimal.

In conclusion it may be stated that there are certain systems that can play a potentially supportive role to caregivers of mentally retarded children; namely, relatives and professional institutions (Gallagher, Beckman, Cross 1983). However such systems need to be mobilized so that mothers of mentally retarded children can benefit from their support.

The findings of the present study seem to suggest that there should be some co-ordination of the services rendered by the formal institutions in the community with those rendered by the informal support system. New support systems such as groups of mothers of mentally retarded children may prove beneficial to mothers caring for their handicapped children at home. The findings further seem to point to a need for community education regarding existing resources and facilities available to caregivers of mentally retarded children.

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